


A research in practice and action with HIV/AIDS community-based organizations: a volunteering component

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1. Introduction

- ◆ HIV/AIDS Community-based Organizations (CBO) operate with limited resources and insecure funding in poor districts or remote regions.
 - ◆ They reach out to marginalized and underserved populations living with HIV/AIDS.
 - ◆ Their health promotion activities take place in **complex** and **unpredictable** settings.
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2. Question

- What is the **practical logic** underlying the actions of a health professional and researcher seeking to generate knowledge forms through diverse modes of communication, verification and educational strategies in this context?

3. Goal

- **Volunteer work** is here as an innovative practice for participatory research approaches.
- The thesis is that active involvement in CBOs allows a deeper understanding of community health action and evaluation.



4. Fieldwork context

- A Provincial Coalition of HIV/AIDS CBOs : the COCQ-sida
- Active participation over a long period of time (since 2004).



5. Theoretical background

- Schön (1986): « thought in action »
- Nowotny, Scott & Gibbons (2001): acknowledge the real context in which scientific knowledge is produced
- Latour (2004): researchers and theorists learn through practices and not thought alone.
- Poland, Frohlich & Cargo (2008): circumstances, events, facts and experience affect knowledge construction in health promotion interventions.

6. Capturing the micro-local picture

- Fassin (1996, 2006): micro-historic, micro-ethnological and micro-sociological aspects of groups faced with social and health problems escape from the global reading by public health
- Polanyi (1964): scientific work can be seen as « artisanal » research involving personal knowledge development
- Bernardou (2004): research practice is a set of concrete actions within the framework of a given fieldwork.

7. The systematization of experiences

- A simple heuristic structure
- Through reorganization and reconstruction of one or more experience, systematization discovers the logic of the life process.
- A rigorous effort to create categories, classify and give order to empirical elements.

(Eizaguirre & al. 2004; Coppens & al. 2005; Zuniga & Luly, 2005; Jara, 2006; Zuniga, 2009)

9. Methodology

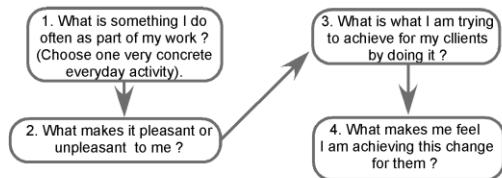
- Data sources : correspondance and written agreements between the CBOs, the Coalition and the researcher
- Auto-ethnographic diary (AUJ): reflexive thoughts & significations of the researcher as an actor inserted into the lived situations (Ellis & Bochner, 2003; Albertin, 2009)
- From 2005-2007, volunteer works
- Collective interviews and discussions
- Narrative vignettes (Miles & Huberman, 2003)

Give order to empirical elements

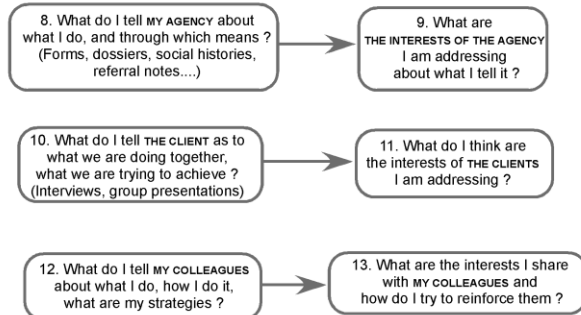
SYSTEMATISATION

SHARING OUR EXPERIENCE : A SYSTEMATIZATION STRATEGY

1° What we do, how we feel, what do we learn ? :



2° To whom do we tell what we do and what we learn and how do we do it ?



3° The road of systematization of our shared experience :

14. My intervenor's challenges as a team member :
How can I DESCRIBE, TALK ABOUT WHAT I DO ?
How can I JUSTIFY the way I go about doing it as a par of our team effort ?
How do I suggest we DEFEND what we do and how we do it ?
How can we use this process to REVINDICATE the means of attaining our aims ?

FIELDWORK, PRACTICES AND EXPERIENCES

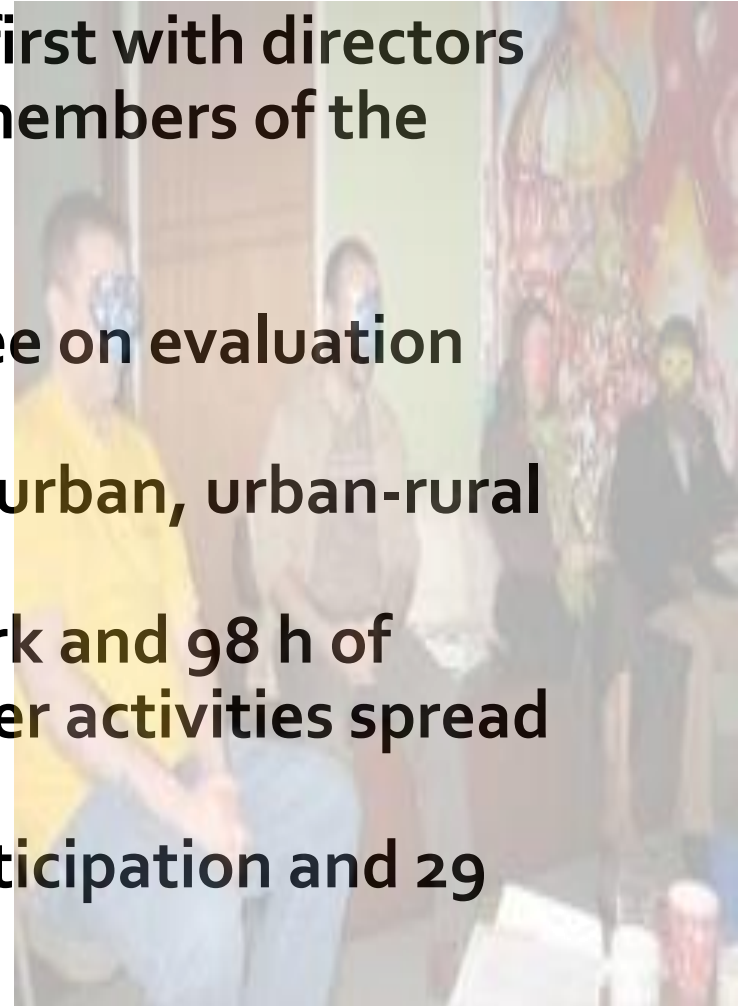


10. The findings

- Being inserted
- Typology of volunteering work and involvement in HIV/AIDS CBOs

11. Being inserted

- **Honest & forthright discussions first with directors and intervenors of the 37 CBOs members of the Coalition**
- **4 Provincial AGM (2004-2007)**
- **Committed of working committee on evaluation (2004-2005)**
- **5 HIV/AIDS CBOs in urban, semi-urban, urban-rural and metropolitan regions.**
- **525 hours (427 h of volunteer work and 98 h of participative observation of other activities spread over 20 months**
- **105 visits linked to volunteer participation and 29 visits to other activities**



12. Discovering the neighborhoods AND ALSO BEING SCRUTINIZED



- The **network** : contacts with users, other volunteers, interveners, coordinators, families, friends.
- The needs: spontaneous invitation to celebrations, educational activities and team meetings
- The organization: observed the researcher as she observed them. What I am feeling? What I am saying to them?

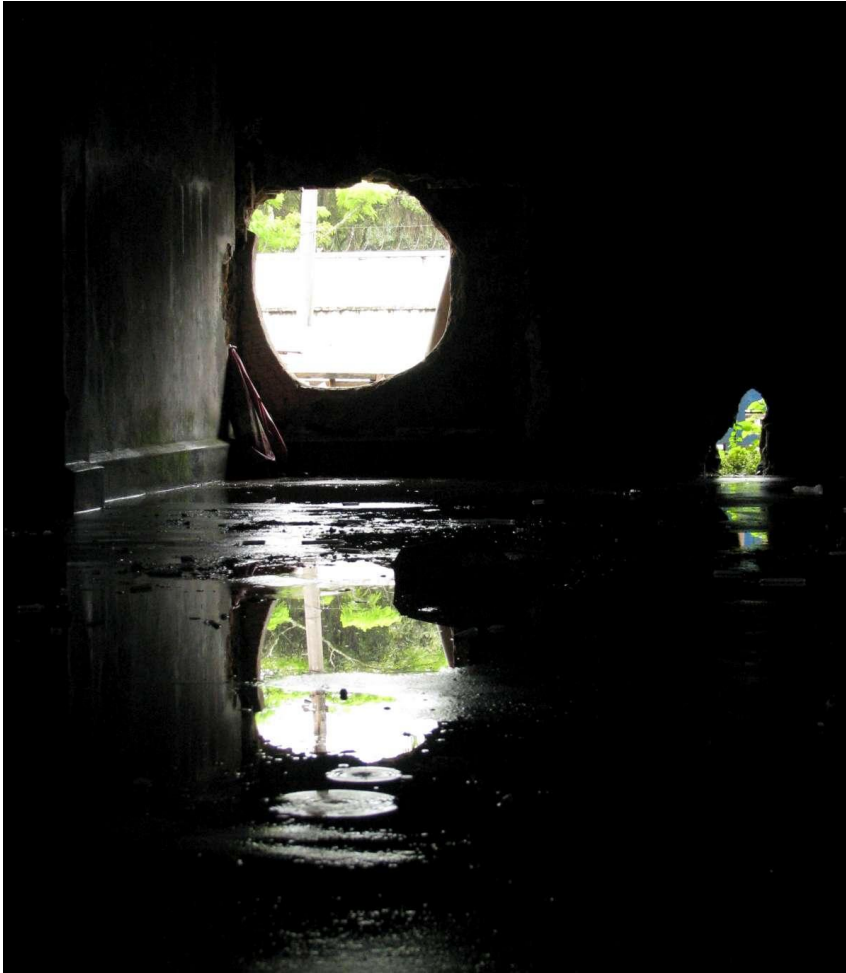
13. Five types of volunteer actions

- Conviviality (191h)
- Caring (53,5h)
- Festive links (62,5h)
- Militancy/fund raising (66h)
- Evaluative collaboration with the Coalition (54h)

14. Conviviality

- Conviviality (Illich 1973) generated personal exchanges and allowed the natural flow of delicate topics such as the struggle to intervene in dangerous settings or the intimate aspects of the personal experience of living with AIDS.
- The visits increased the **consciousness** that places and social contexts.

15. Conviviality...



- Corridors, kitchens, lounges, parks, streets, carts, hospitals (waiting for appointment) and bars appeared to be effective places for talking and sharing.
- In contrast to roundtable discussions, these public settings facilitated more **authentic conversations.**

16. Caring

- **The shift of my conception of « user » to that of « active member » of the collective action.**
- « you work as a nurse, aren't you? »
- The director evaluated the claim with the volunteer tasks accomplished or not with them.
- In other situation, after observing my attitudes towards the users, an intervener revealed that he was living with AIDS.

17. « Why do you want to help me? »

- I accompanied this same person for a year. One day as we were returning from the shopping center, she opened up and told me that she wanted to die... 2 weeks later, an intervener phoned to tell she had passed away.

(AEJ, 2005/12/27)



18. Whose blood is it?

- Despite being washed, the cuticles and the extremities of his fingers remained bloody. The **blood contaminated by HIV and HCV** on his hands was regularly left on door handles, food in the fridge, glasses and cups, sheets; in short, on everything he touched. We tried using regular bandages but his blood continued to seep out. It was not a deep wound that required acute care and which would require his admission to health care services, but it was one that had potential risks for his human contacts. (AEJ, 2007/01/12)

19. Festive links

- **One day, a volunteer colleague invited me to come to in his support group where he was to celebrate a year of drug sobriety (AEJ, 2007/02/24).**
- Going there introduced me to the private network among peers in similar situations
- The emotion was strong when explaining his story
- He interpreted significant life situations in terms of his awareness of himself as someone living with AIDS and being a volunteer.

20. Militancy/fund raising

- **Being part of some fund rising events, I witnessed the CBOs efforts to come to grips with their uncertain financial situation.**
- I participated to an auction for two consecutives years.
- People living with AIDS, volunteers, interveners, directors and other community partners worked together to raise money for emergency requests (foods, transportation, home, special medication and treatments) not funded by the public health system.

21. Advocacy

- **I experimented with some CBOs strategic political actions to make this reality visible for politicians (masks, public declarations, protests, gatherings, reports)**
- Advocacy with PVVIH with lipodystrophy.
- Dressed with masks that we created (to camouflage), we walked to Parliament Hill to meet politicians. However, the police blocked our way.

22. Conclusions: knowing through action

- While the method used in this research project had many similarities to an ethnographic approach, there were differences with regard to its explicit component of community volunteer commitment.
- Service-learning & civic engagement research (Bowdon & al. 2008).
- Ethical engagement goes beyond being a respectful observer.
- **Reciprocal participation:** researcher participates in the community action's processes; community actors participate in the research process (ICASO 2007).

22. Collective service as a socio-political engagement

- The nature of integrated participation (grassroots popular education in Latin America : Fals-Borda, 1979, Brandao & Streck, 2006, Demo, 2008; Vasconcelos, 2008)
- Kind of involvement : **a praxiological life experience [Vivencia]** (Fals-Borda, 1997)



23. Full awareness of the costs of scientific detachment

- Personal point of view, anchored in inner life experiences as a nurse and a researcher.
- Actor's self-production supports the claim that people produce the meanings of their actions (Taylor, 1989, Touraine & Khosrokhavar, 2000)
- Knowing is an active practice of understanding (Polanyi, 1964) and an
- Experimenting society that will accept that « trial-and-error is essential » (Campbell, 1971)
- Transferability in terms of Kuhn (1977) and Schon (1983) : the capacity of research results for creating a « **repertoire of exemplars** » that might serve in similar situations.

24. Grasping the context

- The researcher and the community actors developed a shared conviction that volunteer involvement encourages academics to provide services to the community within the framework of a more **egalitarian partnership**.